

February 10, 2000

Donna Shalala, Secretary
U.S. Department of Health and Human Services
c/o: Assistant Secretary for Planning and Evaluation
Attention: Privacy-P, Room G-322A
Hubert Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201

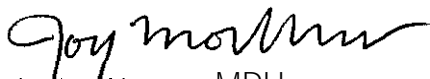
Dear Secretary Shalala,

Attached you will find comments regarding the proposed DHHS privacy regulations and the unique privacy and safety needs of battered women. As you know almost one-third of American women report being a victim of domestic violence at some point in their lives. The health care system is playing an increasingly important role in responding to battered women by identifying and documenting abuse and connecting victims with domestic violence advocates and services.

However, inappropriate use and disclosure of health information regarding abuse poses unique safety threats for victims. Perpetrators who discover that women have disclosed domestic violence can retaliate, further endangering the lives of battered women and their children. Additionally, employers, insurers, and other parties who discover a history of abuse through unnecessary health information disclosure often discriminate against victims. While the proposed regulations offer many protections for all patients, several key issues unique to victims of domestic violence have not been fully addressed. As a family physician and public health professional, I urge you to integrate the enclosed comments in the final regulations to ensure the proper protection for victims of domestic violence.

Please continue DHHS's commitment to improving the lives of battered women by integrating these important comments into the final regulations.

Sincerely,



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Comments to Proposed DHHS Privacy Regulations

General Comments

We are writing to express our concerns with the recently proposed health information privacy regulations. As you know almost one-third of American women report being a victim of domestic violence at some point in their lives. The health care system is playing an increasingly important role in responding to battered women by identifying and documenting abuse and connecting victims with domestic violence advocates and services. Privacy of health information is critical to the safety and well-being of millions of women and children who suffer harm from domestic violence and abuse each year. Strong privacy protections that take into consideration the concerns of domestic violence victims will encourage victims to discuss their injuries and feel safe knowing that their information will remain confidential.

A victim is often concerned about privacy because she fears that her perpetrator will discover that she has discussed the abuse with her provider. A perpetrator who learns that his victim has told her provider about

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the domestic violence could resort to further abuse. Because victims fear that their health information will not remain confidential, many may be reluctant to discuss the violence openly and honestly.

In order to protect victims, many providers do not document domestic violence because they also fear the perpetrator could access the victim's health information and cause additional harm. Providers who discover but do not document domestic violence run the risk that later treating providers will not know the history of violence and misdiagnose the victim. Providers who do not document violence could also reduce the victim's chance of success in legal proceedings against her perpetrator. A complete medical record that fully documents injuries and subsequent health complications from the abuse can be introduced as compelling evidence to corroborate the victim's testimony. Without this corroborative evidence, victims would need to introduce other, less persuasive evidence which could hinder the victim's chance of success. Providers who know that information will remain confidential are more likely to engage the patient, encourage the patient to discuss violence openly and feel comfortable providing a complete record.

For a victim who chooses to be open and honest, privacy concerns only begin when she discusses the violence with her provider. Any communication with the victim at home, including a bill, or email or telephone call to confirm an appointment, increases the likelihood that the perpetrator will intercept the information. Individuals who are concerned about their safety should be permitted to give providers a telephone number and address where the victim feels comfortable that the perpetrator will not discover that she has sought treatment. The Secretary's proposed role would not require providers to honor this request. While the Secretary proposes a right to request restrictions, providers confronted with such a request would likely underestimate the important safety concerns of the victim.

The following recommendations are key to improving the health care, safety and well-being of domestic violence victims. Without these protections, victims of domestic violence will receive inadequate health care services, be less able to pursue effective legal recourse, and be potentially exposed to further violence.

Summary of Recommendations

The regulations can be improved in several important ways to ensure that information about domestic violence and abuse is adequately protected:

- extend protections to paper records
- require covered entities to obtain written authorization for treatment, payment and health care operations
- require entities to use de-identified information when possible
- require entities to use only the minimum amount of information necessary to accomplish the intended purpose of the use or disclosure
- give individuals a true right to restrict use and disclosure where an individual's safety could be jeopardized
- limit use and disclosure of information by benefit administrators (who receive protected health information) to other employees who do not need the information
- specify what information should be included in court and administrative orders, limit disclosures not pursuant to court orders to that which is reasonably necessary, and require persons who request information to provide individuals with notice and opportunity to object to the disclosure
- require that any disclosure for law enforcement be subject to review by a neutral judicial officer
- limit disclosures of directory information when a provider reasonably believes that an incapacitated individual's injuries could be the result of domestic violence
- require that plans and providers receive a signed acknowledgment that the individual has received notice of information practices
- require providers to consider domestic violence when making next of kin disclosures

Applicability

We believe that the regulation should apply to health information in both electronic and paper format. By only covering electronic information, the same concerns about patient confidence that exist today will continue, as many patients will remain reluctant to discuss sensitive health information, even for treatment. Because of the complexity of the health care system, most patients will never know what information, if any, is stored electronically. We are especially concerned that many domestic violence

victims will continue to hide the real cause of their injuries because they fear for their safety. Even if patients are able to determine what information is maintained electronically, they will likely fear that some portion of the information is in paper format. The only way to ensure patient confidence in the health care system is to make the proposed rules applicable to all information.

Definitions

We agree with the Secretary's proposed rule that a minor who lawfully obtains health care services on his or her own exercises the rights of an individual under the proposed rule. For victims of domestic violence or abuse who are minors, this provision would guarantee that family members who are perpetrators could not access information (see also comments for Directory Information and Next of Kin). We are also concerned about minors who may suffer due to inappropriate parental intervention. For example, a daughter who is abused by her boyfriend may fear that if her parents discover the abuse, they will confront her abusive boyfriend in a cursory or inappropriate manner. As a result, the boyfriend could resort to retaliation and further violence.

Treatment, Payment and Health Care Operations

We strongly believe that covered entities should be required to get individual authorization in order to use or disclose protected health information for treatment, payment and health care operations. While the Secretary states that such an authorization is meaningless because individuals must sign the authorization in order to receive treatment, authorizations themselves are very important because they are an "initial moment" in which patients can raise questions about privacy concerns and learn more about options available to them. For many domestic violence victims who are concerned about further violence, this initial moment will help create confidence that their information will be used only for specified purposes.

Providers disclosing information for consultation or referral should be required to verify who is requesting protected health information. We are concerned that victims of domestic violence who receive specialized care (such as reproductive or mental health services) may have their information improperly disclosed to the perpetrator. Under the proposed regulations, a provider who renders specialized services would not be required to consult the patient before disclosing information or even verify who has requested the information. We are concerned that perpetrators could successfully obtain information by using the proposed rule under false pretenses.

The regulations should require a covered entity to protect against inadvertent disclosures of protected health information concerning sensitive health care services (defined as services relating to reproductive health, sexually transmitted diseases, substance abuse, and mental health) by obtaining an individual's authorization prior to communicating with the individual at the individual's home (whether by phone or mail). Individuals seeking sensitive health care services have a heightened concern that information about their medical condition or treatment may be inadvertently disclosed to others in their household, such as roommates, house mates, or family members. The authorization should specifically ask whether the provider or plan can call the individual at home, send communications via email to the individual's home, or send bills to the individual's home. If the individual does not authorize these communications, the individual should provide on the authorization form a phone number or an address for such communications and must indicate how payment will be arranged if payment is due.

Minimum Necessary

We strongly believe that entities should first be required to determine whether de-identified information can be used or disclosed to accomplish the intended purpose. While the proposed rule requires that entities use only the minimum amount of information necessary, the rule does not require the use of de-identified information. We believe that a clear statement that entities must first consider de-identified information is the only way to ensure that the minimum amount necessary standard is adequately implemented.

We also strongly believe that when an entity discloses information at the individual's request, only the minimum amount necessary should be disclosed, unless the individual has indicated otherwise. A victim may authorize a provider to disclose information to a friend or family member in order to discuss her present course of treatment. Under the proposed rule, a provider could disclose the victim's entire medical history including information about domestic violence the victim may have intended to remain confidential.

Where disclosure is not pursuant to a court order, we strongly recommend that only the minimum amount of information necessary to respond to the request be disclosed in judicial and administrative proceedings. While we recognize that litigants may need to access information, we are concerned that covered entities who disclose information would prefer to disclose all information rather than redact sensitive information. Unnecessary disclosure could occur under a number of scenarios, including a subpoena in a personal injury lawsuit where the victim save a history of prior abuse at the provider's request. While some providers, plans or parties may choose to redact the information, some may not—thereby disclosing sensitive personal information. If the holder of information is unclear what information is being requested, the entity should request clarification and should only disclose that information which is necessary. While the Secretary's preamble raises practical concerns about applying the minimum amount necessary standard requirement in judicial and administrative proceedings, we believe that, at a minimum, only information reasonably necessary to respond to a subpoena should be disclosed (see Judicial and Administrative Proceedings)

Law enforcement access to protected health information about victims of crime or abuse should be limited to the minimum amount necessary requirement. Providers who disclose too much information to law enforcement without adequate consideration of the victim's safety increases the likelihood that a perpetrator will discover that the victim was treated for her injuries or disclosed domestic violence (see Law Enforcement). We are also concerned about victims in small communities who can be easily linked to the information even if the victim's name or address is not disclosed. We believe that the minimum necessary requirement would help prevent these types of inappropriate and unnecessary disclosures.

Right to Request Restrictions

An individual should have a true right to restrict the use and disclosure of information that could jeopardize the individual's safety. Women who know that they will suffer further violence from a perpetrator seeing medical records documenting the abuse must be able to access health care without fearing such communications will reach him. A victim of domestic violence needs to be able to place restrictions on the use and disclosure of their information even for treatment, payment and health care operations. A victim also needs to know that a perpetrator who requests information will not be able to locate her. It is essential that a victim who has fled a perpetrator not be found because a provider or insurer gave the perpetrator the victim's new address, either directly or through mailing of an explanation of benefits form. A victim's right to restrict the disclosure of her protected health information should not be dependent on an agreement of a health care provider, who may underestimate the severity of danger. Failing to give a victim of abuse a true right to limit disclosures of such information where the disclosure would endanger her safety will undermine the efforts of the health care community to serve victims and deprive them of necessary care and assistance.

Third parties who provide health care services or issue bills independent of the primary provider, insurer, or institution should also comply with use and disclosure restrictions requested by an individual. If an individual restricts the use and disclosure of information, a provider who agrees to or is aware of a restriction must inform third parties that the information can only be used and disclosed for purposes that do not violate the restrictions. For example, an individual who is referred to an out-of-plan radiologist may be billed separately for the radiology treatment. So, even if the primary provider's bill goes to an alternate address, the radiologist's bill could be sent to the victim's house, inadvertently notifying the perpetrator and endangering her. It should always be the primary provider/institution's responsibility to communicate the restriction to all third parties as a patient often does not know which referrals are billed separately.

component Entities

We strongly believe that the Secretary should expressly state that personnel and benefit administration employees responsible for benefits or managing the day-to-day operation of the health plan are covered by the regulation. The Secretary's preamble appears to cover these employees but we believe this should be made clear in the regulation. We also recommend that the Secretary require personnel departments and employees who handle health care administration to have safeguards to ensure that information is not disclosed to the larger organization. We are very concerned about employers who may improperly obtain information from benefit administrators and use the information inappropriately to make employment decisions (such as promotions job assignments, and even firing). Victims of domestic violence would be likely targets for discrimination even when they perform well on the job. Employees who work within the

health care component must be empowered to deny release of the information to corporate executives and managers outside the health care component unless disclosure is required for health plan administration.

Judicial and Administrative Proceedings

We **strongly** believe that the regulations should **specify** minimum information that must be included in court and **administrative** orders in order to guide those disclosing protected **health** information and to notify those receiving information that the **information** cannot be used or disclosed for other **purposes**. At a **minimum**, court and administrative orders **should**: (1) provide that the **protected** health **information** is subject to court protection; (2) state the nature of the information to be disclosed, and to the extent practicable, **identify** specific information to be disclosed; (3) **specify** to whom the information may be disclosed; (4) specify that such information may not otherwise be **used** or disclosed; and (5) meet any other **requirements** that the **court** or tribunal determines are needed to protect **confidentiality**. These **requirements** are necessary to **ensure** that sensitive information is not released **outside** of the proceedings in a way that could jeopardize the safety of the victim.

We believe that only the minimum amount of information **necessary** to respond to a **subpoena** should be disclosed. If the holder of information is unclear what information is being requested, the entity should request **clarification** and should only disclose that information which is necessary. While the Secretary's preamble raises practical concerns about applying the minimum amount necessary requirement in judicial and **administrative proceedings**, we believe that, at a **minimum**, the Secretary **should require** that **only** information **reasonably necessary** to **respond** to a **subpoena** should be disclosed. While we recognize that it may sometimes be **difficult** for parties responding to requests to determine **exactly** what information the **requesting** party **seeks**, the holder of the protected **health** information **should** not have **blanket** authority to disclose **all protected health** information—only information that is directly responsive to a **subpoena** should be **disclosed**. While a victim may have a long history of domestic violence and other conditions, if the information is not **directly responsive** then it should not be disclosed.

We also strongly believe that the **Secretary** should include a provision prohibiting **disclosure** of **protected health** information **unless** the **individual who is the subject** of the information **has** had (1) reasonable notice of the **subpoena** and (2) **reasonable** opportunity to move the **court**, or **other presiding** official, to quash the **subpoena** on the basis that the individual's privacy interest outweighs the interest of **the person** seeking the information. Under the proposed **rule**, a domestic violence victim may not know **about** a **request** for disclosure of her personal information that could **seriously** endanger her. A notice requirement would ensure that a victim **could** take the **necessary** precautions to make sure that domestic violence information does not reach the **perpetrator**.

Law Enforcement

We are very concerned that domestic violence information may **be disclosed** to law enforcement **officials** **without** any consideration or notice about safety concerns of **domestic** violence victims. The only way to **safeguard** the privacy of domestic violence victims is to require a warrant from a **neutral judicial officer** **prior** to every law enforcement disclosure. A warrant **requirement** is a **familiar** standard in **other federal privacy laws** and has not been shown to interfere with legitimate law enforcement activity. We are also **concerned** that without a warrant **requirement** a victim could **be** deterred from reporting violence if she knows that the police **could access** all of her medical records,

A covered entity should be required to provide notice to a victim **about** any **requests** or **disclosures** of information to law enforcement officials. Information **released** to law enforcement **officials will likely** be used to make an arrest or conduct follow **up investigation**. We are concerned **that** during this process a **perpetrator** may discover, either directly through police interrogation or **indirectly from** witnesses who have been contacted, **that** the victim has **discussed** the abuse with law enforcement **officials** or her provider. Providing notice to the **victim will allow** the victim to take necessary safety precautions. **Because** providers are **already** required to account for **disclosures** we believe that any administrative **burden would** be **insignificant**.

When a **victim** has **requested restrictions** on **uses** and **disclosures** of her health information, the **covered** entity should communicate those restrictions to law **enforcement** officials. **Informing** law enforcement of the **restrictions** would help investigators **understand** a victim's safety concerns. Law **enforcement officials would then** be **better prepared** to help the victim seek protection **during the** investigation.

Directory Information

Because directory information includes the name, location and condition of the patient, a perpetrator could easily locate a victim to commit further violent acts. While individuals who are not incapacitated would have an opportunity to opt out or limit the amount of information to be disclosed, incapacitated individuals would have no protection. A provider who reasonably believes that the injuries of an incapacitated individual could be the result of domestic violence should be prohibited from disclosing the location of the individual. We believe that such a limitation is essential for the safety of domestic violence victims. Providers should be given discretion to disclose the location of the individual to immediate family members who qualify as next of kin and when the provider does not believe the injuries could be a result of domestic violence.

Notice of Information Practices

We encourage the Secretary to require entities to make reasonable efforts to obtain a signed acknowledgment that the individual has received and read the notice of information practices. While we believe that a signed authorization is the best policy, we also believe that a signed acknowledgment could also serve as an "initial moment." (See Treatment Payment and Health Care Operations)

Next of Kin

We are very concerned about situations where a perpetrator who is a next of kin attempts to obtain information about his victim's treatment for her injuries. If the perpetrator discovers that the victim discussed her injuries and identified the perpetrator by name, he could confront the victim. This confrontation may be another violent episode. We strongly believe that where verbal agreement cannot be obtained any disclosure must take into consideration whether the information could jeopardize the safety of the victim.

We are also concerned that the proposed rule does not have adequate verification procedures to identify those who are requesting information. If verbal agreement is not possible, the perpetrator could easily obtain domestic violence information. In the Secretary's preamble (p. 59972), she states that when there is no verbal agreement a verbal inquiry into the identity of the person requesting the information is sufficient. We strongly disagree and believe that an entity should verify the identity of the next of kin who has requested the information. A perpetrator could attempt to obtain information as next of kin while the victim is unconscious in order to find out whether she previously identified him as the perpetrator. By verifying the identity of the person requesting the information, a provider could then make an informed decision as to whether the safety of the victim may be jeopardized.

Right to Restrict

We recommend that the Secretary's proposed right to request restrictions on all information be retained. However, a mere right to request restrictions does not adequately address the safety concerns of victims of domestic violence or the discrimination and safety concerns of others with sensitive health conditions. Victims of domestic violence have immediate safety concerns when information about their treatment is disclosed to the perpetrator. Often perpetrators are angered if they find out that their victims have told a provider about the abuse. As a result, the victim may be in more serious danger of personal harm. There are many ways for perpetrators to discover that the victim has had or is seeking medical attention, or discover the whereabouts of the victim (i.e. by finding a bill or explanation of benefits or notice of appointment in the mail, answering medical history questions posed by an attending health care worker or an insurer, directly asking a provider or insurer, or by false pretenses). The victim should be able to request that, to the extent possible, covered entities not use or disclose protected health information in ways that would alert the perpetrator. Thus, the victim should be able to request that a bill be sent to a different address, or that the perpetrator (if identified) not be given particular health information about the victim, or that only specified persons be given full access to the patient's health information. Not requiring that entities restrict use of information has broad effects. If victims of domestic violence are not adequately assured of the confidentiality of their information, they will be less likely to seek medical attention and counseling. Failing to give victims a true right to limit disclosures of their health information where the disclosure would endanger their safety undermines the efforts of the health care community to serve victims and deprives victims of necessary care and assistance.

We **appreciate** the **Secretary's concern** about the **unworkability** of an absolute right to restrict, but when restrictions concern information that could jeopardize the patient's safety, the safety of the individual outweighs any **administrative burden**. While **restrictions** may be **ignored** or overlooked because the **person handling the information** is unaware of the restrictions, we believe that entities could minimize any oversight by flagging **restricted** information in a noticeable place and **manner** on the information **itself**. All entities who receive sensitive information subject to restrictions by the individual should be informed of and comply with the restrictions.

We are very **concerned** that the **Secretary's** proposed **rule** does not permit individuals to **request** restrictions on the use and **disclosure** of **information** in emergency situations. We strongly believe that **the** fight to **restrict** should apply in emergency situations. A victim who has been harmed by violence may **first turn** to emergency services for aid, and the victim should **be** able to **request** that the **perpetrator** not be told of her condition or **whereabouts**.